

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

SWOHF HONORS AUDRA LAMB

The Southwestern Ohio Hemophilia Foundation is pleased to recognize Audra Lamb as Volunteer of the Year. She was honored at the Annual Meeting on March 4, 2017. Audra has been involved with the SWOHF community for more than 27 years. She started volunteering at a young age because her brother, Eric, has hemophilia B. Over the years, Audra has served on many committees including the Annual Gala, the Bleeding Disorder Awareness 5K, Family Fest and the Brad Miller Birdie Busters Golf Scramble. Her husband, Nick, and two boys, Miles and Holden, can also be seen at most SWOHF's events.



Audra Lamb, SWOHF Volunteer of the Year

In this ISSUE

- p.1 SWOHF Honors Audra Lamb
- p.1 Foundation Welcomes New Staff
- p.2 SWOHF Gala 2017
- p.3 NHF Inhibitor Education Summits
- p.4 Ties that Bond: Nurturing the Needs of Unaffected Siblings
- p.5 2017 Brad Miller Birdie Busters Golf Outing
- p.6 Antacids Can Cause Bleeding
- p.9 NHF's Annual Meeting
- p.11 Be Sure to Friend Us

FOUNDATION WELCOMES NEW STAFF

The Southwestern Ohio Hemophilia Foundation is pleased to welcome two new staff, Karen Kirsch (executive director) and Alison Shoffner (administrative assistant). Karen previously served as Executive Director for the Hemophilia Association of the Capital Area in Washington, DC. Alison previously served on the SWOHF Board of Directors and is a lifelong SWOHF member. Feel free to reach out to Karen or Alison for your questions and concerns.



Karen Kirsch, our new executive director



Alison Shoffner, our new administrative assistant

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CURRENT BOARD MEMBERS:

| | |
|---------------------------------|---------------|
| Chad Shellabarger, President | Denise Croley |
| Lindsay Carlson, Vice President | Dick Miller |
| Debra Smith, Secretary | Eric Shepard |
| Jenny Bostater | Dena Shepard |

Summer 2017

NEXT PAGE: SWOHF GALA 2017



The Southwestern Ohio Hemophilia Foundation
Invites You to Join Us at Our Annual Gala

SWOHF GALA 2017

FRIDAY, JUNE 23, 2017

DAYTON ART INSTITUTE

456 Belmonte Park N. Dayton, OH 45405

at 7:00 p.m. (registration begins at 6:00 p.m.)

THE EVENING WILL INCLUDE:

Heavy Hors d'oeuvres • Beer, Wine & Spirits
Live Music and Dancing — With entertainment by
Dayton's premier cover band, Velvet Crush!!

Cocktail Attire

\$75 per person • Table of 8 for \$750

ONLINE REGISTRATION:

<http://tinyurl.com/swohfgala2017>



National Hemophilia Foundation

INHIBITOR EDUCATION SUMMITS

NHF HAS ANNOUNCED ITS 2017 INHIBITOR SUMMITS.

Inhibitor Summits have been held for more than a decade, providing families affected by inhibitors with the education and support they often need as they face this serious complication.



NHF is hosting three summits. The June summits are closed but the October summits still have space available. Registration opens in July.

- Thursday, June 1 - Sunday, June 4 in Phoenix, Arizona (closed)
- Thursday, June 22 - Sunday, June 25 in Houston, Texas (closed)
- Thursday, October 12 - Sunday, October 15 in Baltimore, Maryland (registration for the Baltimore meeting will open in July 2017)

MORE INFORMATION CAN BE FOUND ON THE WEB
AT THIS LINK:

<http://tinyurl.com/nhfinhibitor>

TIES THAT BOND

NURTURING THE NEEDS OF UNAFFECTED SIBLINGS

BY AMY LYNN SMITH
Reprinted with permission from the
National Hemophilia Foundation

Cristina de la Riva, 23, has always been close to her younger brother, Jorge. In fact, she says they are best friends.

Jorge was diagnosed with severe hemophilia A at birth. His hemophilia immediately became a family affair. “When Jorge was diagnosed, our family was diagnosed,” Cristina says. “We became a team that was going to figure this out together.”

Although she was only 2 years old when Jorge was born, Cristina’s parents told her the truth as soon as she was able to understand it. The family got involved right away with the Lone Star Chapter of the National Hemophilia Foundation (NHF) in Houston.

“When I was little, all I remember of hemophilia was my brother crying because he had a shot, so I related to hemophilia very negatively,” Cristina says. “But later, as my mom became the director of the Lone Star Chapter, then I associated hemophilia with the community, going to bowl-a-thons, going to walks and doing fun stuff.”

“Jorge only lets a few people experience his hemophilia with him, so I think it’s made us closer,” she says. “That’s kind of a gift to the siblings in our community, something that is shared and can be a bonding experience within the family.”

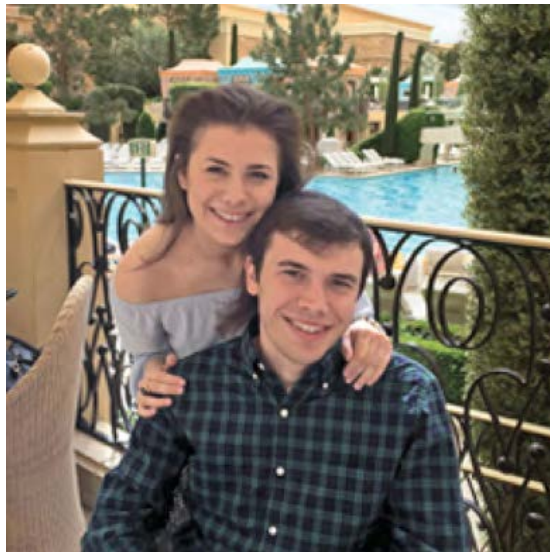
OPEN COMMUNICATION

For Cristina, being the unaffected sibling of someone with a bleeding disorder has been a positive experience overall. In fact, she appreciates the opportunities it has created, such as the chance to advocate and participate in NHF’s National Youth Leadership Institute (NYLI), a three-year leadership training program for young adults ages 18 to 24.

But this is not always the case, according to Jeanne Safer, PhD, a psychotherapist and author of *The*

Normal One (Delta, 2003). The title, she says, came from the unaffected siblings in families of children with disabilities or other challenges who self-identify as “the normal one” in the family.

According to Safer, it’s important to let unaffected siblings talk about their frustrations and fears. “You can’t make somebody feel certain things. You have to allow them to feel what they feel,” she says. Parents should avoid telling unaffected siblings to “count your blessings” if they express negativity about their sibling’s condition. “That squelches normal responses,” says Safer.



Cristina de la Riva (pictured above, with brother Jorge) credits her brother’s hemophilia with making their family closer.

Family members should avoid referring to the sibling with a bleeding disorder as having “special needs.” After all, Safer says, all children have special needs of some sort. Consistently treating the sibling with a bleeding disorder as special can make unaffected siblings feel that they’re not special or that their needs don’t count. Education, observation, or hiding the facts about bleeding disorders from unaffected siblings will only breed fear and uncertainty.

Cristina’s parents let her be present for Jorge’s clotting factor infusions, so she could see exactly what was involved. “I was in on it,” she says. “Otherwise, it would have been this private thing between my father or mother and my brother. I would have felt left out. I would have seen hemophilia as an experience that was separate and foreign to my own.”

What’s more, Cristina’s parents were candid with her about her risk of being a carrier of hemophilia, especially because her mother is a symptomatic carrier. Cristina was tested at age 19 and is not a carrier.

LET THEM SHINE

Safer points out that not all siblings will be naturally close. In fact, some aren’t comfortable being part of their brother’s or sister’s care. She urges parents not to force camaraderie in these relationships. She

also suggests spending some one-on-one time with unaffected siblings.

“Let them be the center of attention regularly,” Safer says. “And let them have their own friends, activities and moments to shine.”

“Your family bleeding disorder doesn’t have to be something negative in your life. In our family, we became closer because of our bleeding disorder,” says Cristina.

LEARN MORE

- NHF’s Steps for Living website offers information for siblings: <https://stepsforliving.hemophilia.org/basics-of-bleeding-disorders>
- Read how to help a child cope with a sibling’s bleeding disorder in this HemAware article: hemaware.org/story/how-help-children-cope-their-siblings-bleeding-disorder



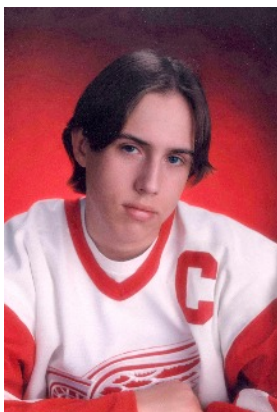
25TH ANNIVERSARY THE BRAD MILLER BIRDIE BUSTERS

Golf Outing to Benefit the
Southwestern Ohio
Hemophilia Foundation

Thursday, August 17, 2017

**Beavercreek Golf Club
2800 New Germany-Trebein Rd.
Beavercreek, OH 45431**

**For more information email
info@swohiohemophilia.org or call (937) 298-8000.**



Brad Miller

In 2010, the Birdie Busters Golf Outing was renamed in memory of Brad Miller, a member of our hemophilia community who passed away at age 29 in October 2008. Brad’s short life was filled with many health challenges, all of which he faced with courage and strength.

We fondly remember Brad’s compassion for others and love for family and friends. Brad is the son of Richard and Mary Miller, long time supporters of SWOHF and brother of Ellyn Miller.

ANTACIDS CAN CAUSE BLEEDING

FDA ISSUES WARNING ON COMMON OTC TREATMENT

Reprinted with permission from the National Hemophilia Foundation



After that pepperoni pizza that gave you heartburn, you may reach for relief in the form of an antacid. But be careful: Some antacids contain aspirin, which is generally taboo for people with bleeding disorders because of the increased risk of bleeding. The US Food and Drug Administration (FDA) released a safety announcement in June, warning consumers to read antacid labels, after receiving reports of serious bleeding in some people.

Antacids that contain aspirin include generics and trade names you may recognize, such as Alka-Seltzer Original and Bromo Seltzer.

According to the FDA, risk factors that increase the likelihood of a bleed in the stomach or gastrointestinal tract include:

- Being older than 60
- Having a history of stomach ulcers or bleeding problems
- Taking other medicines that contain nonsteroidal anti-inflammatories (NSAIDs), such as ibuprofen or naproxen



ADYNOVATE

[Antihemophilic Factor
(Recombinant), PEGylated]

For patients with Hemophilia A, the FDA has now approved ADYNOVATE® for

- + Use in children under 12
- + Use in surgery

PROVEN PROPHYLAXIS +
SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =

moments **YOUR WAY**

*ADYNOVATE allows you to infuse on the same 2 days every week.

The pediatric study (N=73) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months.^{1,2}

+Sixty-six patients (32 patients aged <6 years and 34 patients aged 6 to <12 years) received 40-60 IU/kg of ADYNOVATE prophylactically, twice weekly²

+Children experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds^{1,3}

+38% (n=25) of children experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds¹

Talk to your doctor and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see following page for ADYNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. 2. Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. 3. Data on file; Shire US Inc.

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ADYNOVATE

[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive.

To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Issued 12/2016

161045-ADY-US S24587 01/17



N H F CHICAGO THIS AUGUST

NHF'S 69TH ANNUAL MEETING will be held August 24, 2017 - August 26, 2017 in Chicago, Illinois at the beautiful Hyatt Regency Chicago. The program includes three days full of educational sessions, networking opportunities, and access to the exhibit hall.

Each year the Southwestern Ohio Hemophilia Foundation budgets to send two families to the national meeting. SWOHF will pay for transportation and lodging for one affected individual and a second family member to attend. In exchange, individuals who receive meeting funds agree to be interviewed about their experience for the newsletter and speak at the SWOHF annual meeting.

If you are interested in attending, please email info@swohiohemophilia.org by June 1, 2017. If more individuals express interest in attending than there are funds to accommodate, a drawing will be held to determine who will receive the funding.



EXPLORING THE
NEW FRONTIER
CHICAGO AUGUST 24-26, 2017



BAYER access solutions



Don't let insurance or financial challenges get between you and your treatment

Free Trial Program*

- Enroll today for up to 6 free doses[†]
- KOVALTRY[®], Antihemophilic Factor (Recombinant), or KOGENATE[®] FS, Antihemophilic Factor (Recombinant), is delivered to your home free of charge
- Any patient who has not taken KOVALTRY[®] or KOGENATE[®] FS is able to participate, regardless of type of insurance or if you have insurance

Access to Therapy

Concerned about maintaining access to treatment?

We might be able to provide KOVALTRY[®] or KOGENATE[®] FS at no cost if you are[‡]:

- Experiencing challenges getting insurance coverage for KOVALTRY[®] or KOGENATE[®] FS
- Uninsured or underinsured
- Between jobs and experiencing a gap between insurance coverage

\$0 Co-pay Program[§]

If you have private insurance, you may be eligible for the \$0 Co-pay Program.

- You may be able to receive **up to \$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be started and completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available



Call **1-800-288-8374** 8:00 AM–8:00 PM (ET) Monday–Friday.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Patients currently using KOVALTRY[®] or KOGENATE[®] FS are not eligible for the respective Free Trial programs. Participation in the Free Trial Program is limited to 1 time only per treatment. The medication provided through this program is complimentary and is not an obligation to purchase or use KOVALTRY[®] or KOGENATE[®] FS in the future. Reselling or billing any third party for the free product is prohibited by law.

[†]The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

[‡]The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future KOVALTRY[®] or KOGENATE[®] FS purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

[§]People with private, commercial health insurance may receive KOVALTRY[®] or KOGENATE[®] FS co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.



BE SURE TO FRIEND US



Did You Know that SWOHF Has a Facebook Page?

Be sure to check the page often to keep up-to-date with the happenings of your organization.



<https://www.facebook.com/swohiohemophilia/>

The material provided in *Factor Notes* is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

PUBLISHER

Southwestern Ohio Hemophilia Foundation

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MISSION STATEMENT

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy and services to individuals, their families and the community.

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